

## CAREGIVER RESOURCES

Resources available in the NIH Patient Library  
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<u>Author</u>	<u>Title</u>	<u>Location</u>
- - - - -	<b>Children with Traumatic Brain Injury: A parent's guide (2001)</b>	NEUROLOGY TALK
	Editor Lisa Schoenbrodt presents a lengthy but very readable overview. Ten chapters, all written by medical specialists, educators, and a lawyer, cover a broad range of issues relating to medical treatment; coping and adjustment; the effects on cognition, speech, and language; the resulting behaviors and their modification; educational needs; and legal concerns. Throughout, statements made by parents of other children who have suffered TBI add a personal perspective.	HC 618.92 CHI
- - - - -	<b>An Uncertain Inheritance: writers on caring for family (2007)</b>	SELF & FAMILY CARE
	Casey, a mental health editor and journalist, presents a collection of essays by writers on being cared for as well as on caring for loved ones during a time of illness. Covering an assortment of illness--from Alzheimer's to multiple sclerosis, this collection is both moving and insightful.	HC 362 UNC
- - - - -	<b>What if it's not Alzheimer's? : a caregiver's guide to dementia (2008)</b>	NEUROLOGY TALK
	Beginning with a focus on the medical facts, the first part defines and explores FTD as an illness distinct from Alzheimer's disease. The next section on managing care examines the daily care routine including exercise, socialization, adapting the home environment, and behavioral issues. In the following section on caregiver resources, the contributors identify professional and government assistance programs along with private resources and legal options. This newly revised edition follows recent worldwide collaboration in research and provides the most current medical information available, a better understanding of the different	HC 616.83 WHA

classifications of FTD, and more clarity regarding the role of genetics. A completely new chapter 5 enlightens the reader about the various drugs that are now being used with FTD patients and also delves into a number of nonmedical options.  
 --From product description

<b>Adamec, Christine</b>	<b>How to Live with a Mentally Ill Person: a handbook of day-to-day strategies (1996)</b>	<b>BEHAVIORAL HEALTH</b>
	<p>Provides information for caregivers to people with serious mental illnesses, discussing how to provide effective care without sacrificing personal well-being or the needs of other family members, with advice on topics such as ensuring the patient takes his or her medication, where and how to get financial aid, and dealing with legal, hospital, and insurance systems.</p>	<p><b>HC</b> <b>362.2</b> <b>ADA</b></p>
<b>Amador, Xavier Francisco</b>	<b>I am Not Sick, I don't Need Help: how to help someone with mental illness accept treatment (Revised &amp; Updated Ed. 2007)</b>	<b>BEHAVIORAL HEALTH</b>
	<p>Using his extensive and internationally acknowledged expertise in the field of psychology as well as being the brother of a schizophrenic, Amador presents practical advice and guidance on how to listen, empathize, and guide a loved one to understand and accept treatment options. This book is divided into 3 sections which deal with denial, how to present and offer help, and how to handle either the acceptance or backlash of your loved one after they're presented with treatment options.</p>	<p><b>HC</b> <b>616.85</b> <b>AMA</b></p>
<b>Brunvoll, Laurel Seiler</b>	<b>Life on Hold: finding hope in the face of serious illness (2001)</b>	<b>SELF &amp; FAMILY CARE</b>
	<p>Written by the father-daughter team of Laurel Seiler Brunvoll and David G. Seiler. The authors speak poignantly from their own family experience of losing a mother/wife to ovarian cancer. The book's frank advice and faithful perspective offers comfort and understanding of the emotional struggles families face in the time of illness.</p>	<p><b>HC</b> <b>248.8</b> <b>BRU</b></p>
<b>Buckingham, Robert W.</b>	<b>When Living Alone Means Living at Risk: a guide for caregivers and families (1994)</b>	<b>SELF &amp; FAMILY CARE</b>

	<p>This important book brings together an impressive array of experts who seek to assist family and friends in recognizing the danger signs that surround an at-risk elder, and points out the vital, but often subtle, distinctions between types of behavior that give cause for worry and those which can best be described as idiosyncratic. The essays offer suggestions for appropriate assistance that maintains respect for elder autonomy and freedom.</p>	<p>HC 362.1 BUC</p>
<b>Canefield, Jack</b>	<p><b>Chicken Soup for the Caregiver's Soul (2004)</b></p> <p>A dose of inspiration for caregiving professionals and the millions of souls who help care for family and friends. This collection offers a respite to those who give care through inspiring and uplifting stories about the work they do and its power to transform lives. Through awe-inspiring glimpses of real-life experiences of others, readers will find the motivation to overcome a challenging day, welcome recognition for their selfless contributions, and the encouragement to continue making a positive difference in others' lives.</p>	<p>SELF &amp; FAMILY CARE</p> <p>HC 158.1 CAN</p>
<b>Cooke, Margaret</b>	<p><b>Ways You Can Help: creative, practical, suggestions for family &amp; friends of patients and caregivers (1996)</b></p> <p>This book offers hundreds of thoughtful ideas to brighten the day of a patient or caregiver. From taking care of a pet to shopping for groceries, the advice in this invaluable guide is designed to provide exactly what's needed in every situation.-- <i>From product description</i></p>	<p>SELF &amp; FAMILY CARE</p> <p>HC 362.1 COO</p>
<b>Denholm, Diana B.</b>	<p><b>The Caregiving Wife's Handbook: Caring for your Seriously Ill Husband, Caring for Yourself (2012)</b></p> <p>Provides guidance and advice on how couples can communicate and relate better—and make good choices during his illness so that their life together meets the needs of both.</p>	<p>SELF &amp; FAMILY CARE</p> <p>HC 362.17 DEN</p>
<b>Donnan, Geoffrey</b>	<p><b>After a Stroke: a support book for patients, caregivers, families and friends (1992)</b></p> <p>Authored by a neurologist, the contents</p>	<p>NEUROLOGY TALK</p> <p>HC 616.8</p>

	include basic information on strokes: definition, consequences, effects on the family, treatment, rehabilitation and prevention.	DON
<b>Dunn, Hank</b>	<b>Hard Choices for Loving People: CPR, artificial feeding, comfort measures only, and the elderly patient (2001)</b>	<b>TO GRIEVE WELL</b>
	Hank Dunn draws on his extensive experience as a chaplain in a nursing home, hospice program and hospital. In <i>Hard Choices</i> he shares stories of many of the patients and families he has helped guide through this most difficult and important time in their lives.	HC 362.1 DUN
<b>England, Diane</b>	<b>The Post-Traumatic stress Disorder Relationship: how to support your partner and keep your relationship healthy (2009)</b>	<b>BEHAVIORAL HEALTH</b>
	No matter what crises caused your loved one to suffer from post-traumatic stress disorder (PTSD), you suffer right alongside them. In <i>The Post-Traumatic Stress Disorder Relationship</i> , you'll see that you can have a healthy relationship, in spite of a stressful and debilitating disorder.-- <i>From Book Jacket</i>	HC 616.85 ENG
<b>Hughes, Rose Mary</b>	<b>A Better Life for the Chronically Ill: a guidebook for creative caregiving (2001)</b>	<b>CHRONIC ILLNESS</b>
	Creative ideas to make life more fulfilling and fun for a chronically-ill or long-term confined loved one.	HC 362.1 HUG
<b>James, Vaughn E.</b>	<b>The Alzheimer's Advisor: a caregiver's guide to dealing with the tough legal and practical issues (2009)</b>	<b>NEUROLOGY TALK</b>
	James (law professor, Texas Tech U.) describes the symptoms and stages of Alzheimer's Disease and explores the legal and ethical dilemmas that come with the diagnosis and progression of the disease. Separate chapters address the estate plan, medical advance directives, guardianship, legal liability, long-term care insurance, and the legal impact of moving an Alzheimer's patient across state lines. -- <i>Annotation ©2009 Book News, Inc., Portland, OR (booknews.com)</i>	HC 344.7304 JAM
<b>Kalian, Kathy</b>	<b>Midwife for Souls: spiritual care for the dying (2006)</b>	<b>TO GRIEVE WELL</b>

	<p>This excellent book helps us to better understand the common patterns and interconnections of human life and death in order to make us all more compassionate emissaries of love to one another. <i>Midwife for Souls</i> deals not only with living people preparing to die, but with dying people preparing to live. --Fr. Michael Mannion, Author and Lecturer</p>	<p>HC 259.4 KAL</p>
<b>Katz, Rebecca</b>	<p><b>One Bite at a Time: nourishing recipes for people with cancer, survivors, and their caregivers (2004)</b></p> <p>A collection of 90 recipes, nutritional information, and anecdotes from cancer survivors as well as those who cared for them.</p>	<p>CANCER CONCERNS  HC 616.99 KAT</p>
<b>Keene, Nancy</b>	<p><b>Childhood Leukemia: a guide for families, friends &amp; caregivers (2010)</b></p> <p>This parent guide covers not only detailed and precise medical information about leukemia and the various treatment options, but also day-to-day practical advice on how to cope with procedures, hospitalization, family and friends, school, social and financial issues, communication, feelings, and, if therapy is not successful, the difficult issues of death and bereavement. Woven among the medical details and the practical advice are the voices of more than 150 parents and children who have lived with leukemia and its treatments.</p>	<p>CANCER CONCERNS  HC 618.92 KEE</p>
<b>Kushner, Harold</b>	<p><b>When Bad things Happen to Good People (1989)</b></p> <p>Transcending particular faith issues, this Rabbi addresses the universal and ultimate question- the meaning of suffering in a God-centered Universe.</p>	<p>SELF &amp; FAMILY CARE  HC 296.3 KUS</p>
<b>McQuellon, Richard P.</b>	<p><b>The Art of Conversation through Serious Illness: lessons for caregivers (2010)</b></p> <p>This book is about how to be an encouraging caregiver and friend under the most difficult circumstances, when the possibility of death is all too real. The authors consider how to best listen to and speak with one facing life-threatening illness, with lessons on being a primary</p>	<p>SELF &amp; FAMILY CARE  HC 616 MCQ</p>

conversation partner, becoming properly empathic and receiving empathy, maintaining everyday conversation, using platitudes appropriately, understanding healthy denial, and talking about dying.

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| <b>Mace, Nancy L.</b>              | <b>The 36-Hour Day: a family guide to caring for persons with Alzheimer disease, related dementing illnesses, and memory loss in later life 4<sup>th</sup> ed. (2006)</b>  | <b>NEUROLOGY<br/>TALK</b>         |
|                                    | Explains what dementia is, and offers advice to individuals charged with the care of someone suffering from a dementing illness, discussing evaluation, medical treatment, problems in independent living and daily care, medical concerns, and other topics.  | <b>HC<br/>616.8<br/>MAC</b>       |
| <b>Meyer, Maria M.</b>             | <b>The Comfort of Home for Stroke: a guide for caregivers (2007)</b>   | <b>NEUROLOGY<br/>TALK</b>         |
|                                    | This complete guide helps caregivers, family members, and stroke survivors understand the day-to-day issues faced by care providers. It guides readers through every stage of care, from explaining different kinds of strokes to understanding personality changes brought on by the illness. Other topics covered include how to prevent strokes from recurring, making the home safe and comfortable, returning to work after a stroke, and preventing caregiver burnout. | <b>HC<br/>649.8<br/>MEY</b>       |
| <b>Milstein, Linda<br/>Breiner</b> | <b>Giving Comfort: what you can do when someone you love is ill (1994)</b>   | <b>SELF &amp;<br/>FAMILY CARE</b> |
|                                    | Discusses how to make loved ones who are sick more comfortable and ways to provide them with emotional support, relating tips for meaningful visits, ways to counteract a hospital's impersonal environment, and suggestions for how to get necessary information from medical personnel.  | <b>HC<br/>610.7<br/>MIL</b>       |
| <b>Mueser, Kim T.</b>              | <b>Coping with Schizophrenia: A Guide for Families (1994)</b>  | <b>BEHAVIORAL<br/>HEALTH</b>      |
|                                    | Information, advice, and practical tools. Strategies for: preventing crises, managing stress, overcoming alcohol and drug abuse, dealing with depression, regulating medication, finding community resources, establishing household rules, improving quality of life for the whole family. Recommended by the National Alliance for   | <b>HC<br/>616.89<br/>MUE</b>      |

the Mentally Ill.

<b>National Cancer Institute</b>	<b>Understanding Cancer Clinical Trials</b>  Produced by the National Cancer Institute, this informative DVD provides an overview of what's involved when participating in a cancer research studies & trials as well as discussing some of the most common concerns people usually have during the decision making process.	<b>DVD UND</b>
<b>Robertson, Laurel</b>	<b>Laurel's Kitchen Caring: recipes for Everyday home caregiving (1997)</b>  The charm and compassion of Laurel Robertson--bestselling author of the popular LAUREL'S KITCHEN--make this book of wholesome vegetarian recipes the perfect "nurse's aide" for any caregiver. Laurel includes uplifting stories, advice and inspiration for caregivers, invaluable ideas for administering medicine, and original suggestions for making mealtimes a pleasant occasion, even when the patient can't eat much.	<b>SELF &amp; FAMILY CARE  HC 641.5 ROB</b>
<b>Rosen, Laura Epstein</b>	<b>When Someone you Love is Depressed: how to help your loved one without losing yourself (1996)</b>  Discusses what depression is and how it can be recognized in family members and friends and examines some of the methods for treatment.	<b>BEHAVIORAL HEALTH  HC 616.85 ROS</b>
<b>Sheeley, Gail</b>	<b>Passages in Caregiving: turning chaos into confidence (2010)</b>  In this guide, literary journalist & best selling author, Sheeley, provides insight, advice, and guidance on the eight stages of Caregiving as well as, presenting helpful tips, strategies and poignant stories from experienced caregivers.	<b>SELF &amp; FAMILY CARE  HC 362 SHE</b>
<b>Siegel, Bernie S.</b>	<b>Help me to Heal: a practical guidebook for patients, visitors, and caregivers (2003)</b>  This is a practical guidebook for patients, visitors, and caregivers. It contains essential tools, strategies and resources for healthy hospitalizations and home convalescence.	<b>SELF &amp; FAMILY CARE  HC 362.1 SIE</b>
<b>Siles, Madonna</b>	<b>Brain, heal thyself: a Caregiver's new Approach to recovery from stroke, aneurysm,</b>	<b>NEUROLOGY TALK</b>

**and traumatic brain injuries (2006)**

"Part memoir, part recovery manual, *Brain, Heal Thyself* is a guidebook for unexpected caregivers. Siles recounts moment-by-moment the journey of her friend Eve's near-fatal aneurysm to ER to rehab center to at-home care and, finally, to recovery. Includes visualizations and subliminal methods for invoking the power of emotions and the subconscious mind in the healing process"-- Provided by publisher.

HC  
362.196  
SIL

**Smith, Douglas C. Caregiving: hospice-proven techniques for healing body & soul (1997)** SELF & FAMILY CARE

One of America's leading hospice experts offers practical, easy-to-follow advice for caregivers and a holistic approach to treating the infirm or the terminally ill. Included are easy-to-follow techniques and practical tools for improving care: assessment techniques dialogues meditations life reviews breathing exercises body revitalization methods ways that patients can evaluate and improve their own care and many others. Filled with inspirational stories and effective guidance, *Caregiving* also addresses how to communicate with difficult patients and those in denial, how to facilitate non-stressful family interaction, and other important topics.

HC  
362.1  
SMI

**Niemi, Lisa Worth fighting for: love, loss and moving forward (2012)** SELF & FAMILY CARE

The wife of the late Patrick Swayze presents an account of grief, loss, caregiving and moving on while sharing stories about their final months together and discussing their teenage romance, dance careers, and thirty-four-year marriage.

HC  
921  
SWA

**Torrey, E. Fuller Surviving Manic Depression: a manual on Bipolar Disorder for Patients, Families, and Providers (2002)** BEHAVIORAL HEALTH

The well-known author of *Surviving Schizophrenia*, presents here (with Michael B. Knable) a similar work on manic depression. Symptoms, causes, treatments, medications, new studies and research, and special problems such as drug abuse and violence are all addressed with intelligence and compassion.

HC  
616.89  
TOR

**Torrey, E. Fuller Surviving Schizophrenia: a manual for** BEHAVIORAL

**families, patients, and providers (2006) HEALTH**

Written by a research psychiatrist specializing in schizophrenia. Describes the nature, causes, symptoms, treatment, and course of the illness. Also includes chapters on living with schizophrenia, from both the patient's and the family's view. **HC 616.89 TOR**

**Turley, Susan Medical Language: immerse yourself (2007) REFERENCE**

A comprehensive text which serves as an excellent reference for those wanting to gain a basic yet fundamental understanding of medical terminology so that it may be used in a real life context. **REF 610.1 TUR**

## **FINANCES & BENEFITS**

**- - - - - Nolo's Guide to Social Security Disability: getting & keeping you benefits (2006) DISABILITY RESOURCES**

This excellent resource explains in plain English the programs associated with disability, the means of applying for disability benefits for adults and children, getting benefits during the application process, proving you are disabled, and understanding who decides your claim and how they decide, the fine points of impairment and ability, how age and education matter as much as work experience, the reasons you may be denied benefits, appeals, what to do once you are approved, and your right to legal and other representation. The CD-ROM includes information on how the Social Security Administration categorizes and defines medical disabilities. --Annotation ©2007 Book News, Inc., Portland, OR (booknews.com) **HC 368.4 NOL**

**Brody, Jane E. Jane Brody's Guide to the Great Beyond: a practical primer to help you & your loved ones prepare mentally, legally, and emotionally for the end of life (2009) SELF & FAMILY CARE**

A guide to proactively prepare for the end of life covers topics ranging from financial planning and medical issues to emotional considerations, with advice on health care proxies, wills, funeral preparations, and palliative care. **HC 616 BRO**

**Northrop, Dorothy Health Insurance Resources: a guide for people with chronic disease and disability DISABILITY RESOURCES**

(2007)

This important resource contains a variety of options for people living with disability and chronic health conditions to maximize their rights and entitlements within the health care system. It is an indispensable resource for anyone who is uninsured underinsured, or who has questions about insurance and doesn't know where to begin. Updated to reflect changes since the first edition, the book contains information on Medicaid, Social Security disability insurance, SSI, COBRA, state high risk pools, pharmacy assistance programs, and much more.

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368.4  
NOR

## Relaxation & Stress Management

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**Caregiver Relief: guided imagery for relaxation (74 minutes)**

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This a guided imagery hypnosis CD designed to relieve the stress brought on by caregiving. It uses a mix of progressed relation and guided imagery meditation along with binaural music.

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**Yoga for Beginners (100 minutes)**

DVD  
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Relieve tension and revitalize yourself as internationally acclaimed yoga instructor, Patricia Walden, introduces a complete range of yoga relaxation poses. Along with the DVD, a 46 page booklet is included which describes the poses as well as the health benefits of yoga.

Gurgevich, Steven

**Relax Rx: a mind-body prescription for relaxation and well-being (2008)**

HC  
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GUR

Dr. Steven Gurgevich, a mind-body medicine expert, presents guided trancework sessions and self-hypnosis techniques which can be used to reduce physical tension, relieve anxiety, and create inner calm.

Illing, David

**Reduce stress and Anxiety: hypnotic and subliminal learning program (2004)**

HC  
TB  
ILL

High negative stress can be very wearing on the body and lead to many health problems. The purpose of this CD is to increase your ability to successfully deal with the challenges of living and to decrease how much you go into high stress

states.

Lalvani, Vimla	<b>Classic Yoga for Stress Relief (1999)</b>	613.7 LAL
	Color illustrations demonstrate yoga exercises to relieve stress, covering energy boosters, relaxation moves, meditation and visualization, and remedial yoga.	
Naparstek, Belleruth	<b>For Anyone Concerned with General Wellness (2001)</b>	HC TB NAP
	Designed to uplift and relax; help the body eliminate unhealthy cells and tissue; cleanse and clear; support healthy new growth; invoke a sense of connection with the universe to strengthen mind, body, and spirit. [42 min.]	
Naparstek, Belleruth	<b>A Guided Meditation to help with Caregiver Stress [PLAYAWAY]</b>	HC TB NAP
	Helps to remind the caregiver of their own strength, goodness, tenacity & resourcefulness. The imagery affirms the generational values being carried forward. It notes the invisible forces of love and support surrounding the listener. And it underlines the need for self-care, self-consideration. Designed to also provide relaxation and balance; sustain motivation; reduce isolation; acknowledge the difficulties without sugar-coating them; help release any accrued resentment; and restore hope for the future. With affirmations.	
Naparstek, Belleruth	<b>A Meditation to Help you with Healthful Sleep (2000) [PLAYAWAY]</b>	HC TB NAP
	Designed to promote peaceful sleep; create relaxed feelings of safety and calm; release muscular tension in the body; clear mind of worry and obsessive thinking; heighten a sense of protection and support. Followed by continuous music. [60 mins.]	
Naparstek, Belleruth	<b>A meditation for Relaxation &amp; wellness (2001)</b>	HC TB NAP
	Designed to promote feelings of peace, calm, safety and support; reduce anxiety and stress; encourage hope, confidence, balance and optimism. To help face any stressful situation, or for general anxiety. [38 min.]	

## EN ESPAÑOL

- - - - -	<b>Como Ayudar a Los Niños: a afrontar la situación cuando un ser querido esta enfermo y a punto de morir (2008)</b>	<b>ESPAÑOL</b>
	Este folleto contiene consejos que los adultos pueden utilizar para ayudar a los niños a afrontar la enfermedad terminal de un ser querido. Incluye las herramientas necesarias para apoyar a sus hijos antes, durante y después de su ser querido de la muerte. La información se aplica a los niños de todas las edades.	<b>SP 155.9 HEL</b>
<b>Coleman, Norman</b>	<b>Que Hacer con un Diagnostico de Cáncer? : la información para atender, hacerse cargo, elegir tratamientos y lograr la sanación (2008)</b>	<b>ESPAÑOL</b>
	Esta completa guía describe el proceso desde el diagnóstico de cáncer para las opciones de tratamiento disponibles, incluyendo las posibilidades del paciente de la supervivencia y calidad de vida futura, y proporciona a los pacientes una lista de verificación para registrar los datos importantes.	<b>SP 616.99 COL</b>
<b>Dunn, Hank</b>	<b>Decisiones Difíciles Para los Seres Queridos: RCP, alimentación artificial, medidas paliativas y el paciente con una enfermedad que amenaza su vida (2002)</b>	<b>ESPAÑOL</b>
	Hank Dunn se basa en su amplia experiencia como capellán en un programa de residencia de ancianos en hospicios y hospitales. En este libro, el comparte historias de muchos de los pacientes y sus familias quienes el ha ayudado a guiar a través de estos momentos tan difíciles e importantes en sus vidas.	<b>SP 362.1 DUN</b>
<b>Meyer, Maria M.</b>	<b>La Comodidad del Hogar: guía ilustrada y detallada de cuidado y asistencia (2002)</b>	<b>ESPAÑOL</b>
	Esta verdadera guía aborda muchos asuntos relacionados con el cuidado de la persona en casa. Los temas incluyen la preparación del hogar, terapia (física, ocupacional, del habla, de masaje, etc.), la dieta y nutrición, el manejo de emergencias, entre muchos otros. Entrega ayuda respecto de temas tales como: hacer la casa más segura y cómoda para las personas que tienen	<b>SP 649.8 MEY</b>

necesidades especiales; ayudar en actividades rutinarias, como ir al baño, el aseo, traslados a y de la silla de ruedas; evitar las infecciones y enfermedades; atender las necesidades particulares de un enfermo de Alzheimer; y evitar el agotamiento mientras se realizan todas esas tareas.

**Sept. 2012--Mjc**